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ABSTRACT

The presence in the family of a child with a disabling condition frequently creates or intensifies stress between husband and wife. By forging and strengthening marital bonds and creating an environment that fosters teamwork, openness, and caring, the marriage partnership will be a source of support and renewal. Reactions to the birth of a baby with a disability include withdrawal, self-sacrifice, and disagreements over child-rearing practices. The father's reaction may be to distance himself from the entire situation, leading to the mother's feeling of being alone or trapped. The marriage partners should share their feelings and share responsibilities. Each spouse should have time each day to spend totally focused on himself or herself. In addition, parents should take time to spend with each other. A list of do's and don'ts is included in the periodical issue. In addition, the issue contains an article about gift selection for children aged 10 and older, and an article about being the single parent of a special child. (JDD)

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NURTURING YOUR MARRIAGE RELATION- SHIP

The presence in the family of a child with a disabling condition frequently creates or intensifies stress between husband and wife. Often the joys and expectations normally associated with parenthood are clouded by sorrow and mingled with a pervasive concern over what lies ahead. Families with a disabled child needn't buckle under, however, despite their situation. It isn't the disability *per se* that tears apart the marital fabric but rather how each spouse reacts to the circumstances *and* to each other. Ideally the marriage partnership should be the main source of support and renewal, especially in times of trouble. In this issue we will focus on ways to forge and strengthen marital bonds and create an environment that fosters teamwork, openness and caring.

The marital relationship

The birth of a baby is an emotional as well as physical event. When that baby is born disabled the parents experience sadness and grief rather than the pleasure

and delight felt at the birth of a normal child.

Withdrawal reaction. Too often these feelings are so painful they cannot be examined, let alone shared with one's partner. By nature some people repress unpleasant thoughts, but guilty feelings and resentments are there whether one acknowledges them or not. Even strong marriages can falter if the repressed pain results in withdrawal. Painful emotions that lie dormant can surface later as anxiety or irrational anger shown in the form of bickering, backbiting and other antagonistic behavior. Fear of the unknown or uncertainty over the child's condition often

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L. Murphy



translates into quick tempers or angry words.

Self-sacrifice. The picture is complicated when one spouse devotes all his or her energy to the disabled child to the detriment of any quality time spent with the other partner. Often unconscious feelings of guilt underly this self-imposed martyrdom. The harassed mother, for example, who is too worn out from hovering over the child to go out with her husband is unwittingly sacrificing the companionship that solidifies marital ties.

Disagreements over child rearing practices are typical in every

family with a young child. For example, do we let the baby cry or go to her right away? Because the special child's dependency stages are often prolonged, however, this type of argument tends to go on and on.

How and when to discipline the disabled child creates another set of problems, especially if one parent is more lenient than the other. Not knowing how much the child understands or feeling sorry for her one day and not the next undermines consistent handling. Dissensions between father and mother can thus flourish.

Improving the father's role

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Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.

Often the mother of the disabled child feels alone or trapped, pointing the finger of blame at the father for his *lack of interest*. Taking care of children, despite some changes in attitude towards the female role, is still largely considered "woman's work," especially when the child's condition warrants an inordinate amount of time and tender care.

Our society also holds on to the belief that displaying visible signs of grief or even emotion is somehow unmanly or weak. Although the father may be experiencing the same intense pain as the child's mother he is compelled to forfeit the right to display his feelings or run the risk of being considered unmasculine. Sometimes having a less-than-perfect child is perceived by the father as a threat to his self-esteem and masculinity. His chief defense, therefore, is to *distance*



himself from the entire situation. A father's support group or professional counseling is helpful, giving the father permission to ventilate his pain and gain release.

Sharing feelings. One way to encourage your partner to talk about his feelings is to be open about your own. If, for example,

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you feel dismay about going into a supermarket where you are bound to see mothers taking their normal children for granted, share this sensitivity with your spouse. If that phone call from your mother about the other grandchildren's accomplishments leaves you feeling discouraged, use this as an opportunity to discuss hurt feelings. By honestly expressing your innermost feelings and concerns without succumbing to self-pity you create an environment in which your partner can reveal his thoughts and fears as well.

Share *all* the feelings—good and bad. If, for some reason, your spirits are up and you feel optimistic, let him know that the future doesn't look so grim. Getting in the habit of exchanging emotional intimacies enriches the marriage bond.

Sharing responsibilities. Even though many fathers are willing to help out, the beleaguered mother's most frequent complaint is that it's not enough or not the right kind of help.

In many cases this situation arises because the mother unconsciously excludes the father from gaining enough information on day-to-day procedures. He doesn't know the most efficient method of feeding, dressing or

bathing the child because in most instances he hasn't been shown what to do. Poking fun at his attempts at child care will only turn him off completely. It's unwise to ask for help and then criticize the helper!

Fathers are also faulted for not spending enough time with their children or for not taking an active role in their welfare. This is often true because teacher conferences and visits to therapists or doctors usually coincide with the father's working hours. Scheduling some of these appointments during evening office hours or on weekends when the father is available is bound to encourage interest. Going together to open school nights, parent meetings and conferences will help develop a teamwork attitude. When it is not feasible to go together the parent who does attend should make a concerted effort to pass along all the pertinent information. The more informed the father is about his child and the child's condition the more likely he is to become a concerned parent. Couples who perceive themselves as a team experience much less stress and report more satisfaction with their marriages.



Learning to nurture

The best way to feel good about your marriage is to feel positive about yourself. It is extremely difficult to sustain the marriage or nurture each other unless both partners have learned ways of replenishing their own reserves. Unfortunately a woman's need to nurture others often overshadows the need to nurture herself. The physical and emotional demands of caring for a disabled child and accompanying responsibilities are often so draining they leave the woman too exhausted to be interested in anything else.

Set aside time. It may be possible to set aside only thirty minutes or less each day. Even this short time will serve to refresh and invigorate you if spent totally focused on yourself. Think of *one* thing that will put a sparkle in your day. Perhaps it's a relaxing bath, a pampering manicure, a fascinating book you can't put down. Pursue some hobby or take up a new one.



Go for a walk, jog, work on needlepoint, birdwatch, garden, tend house plants. Choose an activity that will take your mind off things, one that absorbs as well as delights. Get in the habit of finding



pleasurable time throughout the day.

Each spouse should have time to pursue special interests alone if desired. The time spent apart from each other and family concerns needn't be long. The goal is to return to each other and the demands of the family with a refreshed outlook.

Finding time. Hard-pressed special parents frequently dismiss the idea of going out or enjoying each other's company because of the constraints of caring for their disabled child. A restructuring of the daily routine might help, however. It will take cooperation and a good humored approach. For example:

- Divide the chores. This might require crossing gender lines as father cooks or cleans up after dinner while mother does the bedtime chores. Sharing the work load and household chores gets them done efficiently leaving more time for each other.

- Develop consistent bedtime hours. Completing evening chores in a timely fashion and getting children to bed as part of an accepted routine will leave uninter-

rupted time each evening to share some quiet moments.

Get help. Get a babysitter or exchange babysitting time with other parents, enlist the aid of grandparents, avail yourself of respite care. Don't feel guilty about finding time for yourself or leaving your youngster in the care of others. Short periods of time away from your youngster should leave you both with a sense of renewal.

Be careful you don't fall into the trap of spending your precious time alone together dwelling on the problems posed by your child. If this is the case, choose an activ-

ity that requires your undivided attention—a movie or play, a ball game, bowling, skiing or some other compelling pursuit.

Make a date. Make a specific date with your spouse as often as you can. Go out for breakfast or schedule time when you can just chat with each other. Think back to what it was like *before* you had children. What were your favorite activities? Try to recreate that time in your life. Letting each other know that you are in this together will give you both the needed lift to go on no matter what.

Do's and don'ts

Do seek professional advice or marriage counseling if your differences can't be resolved, are extreme or of unusual duration or become abusive.

Do find out all you can about your child's disability. Just knowing what to expect and how to prepare for eventualities can improve your own feelings of competency and reduce stress.

Do get to know other parents of children with similar handicaps. Knowing that others are facing the same things makes it easier to bear. More experienced parents often have helpful hints as well.

Don't be embarrassed to ask others for help. Everybody needs

help, and the sooner you ask for it the better. The danger is in *not* getting help until you are in desperate circumstances.

Don't suffer in silence. If something is troubling you, it's best to get it out in the open. Harboring bad feelings can lead to depression and only worsen the situation.

Do remember that how you say it is every bit as important as what you say. Whining tones, complaints or an angry voice not only put your spouse on the defensive but can precipitate retaliation. Rephrase questions or comments. For example, instead of "You are never around when I need you," try saying "Is there some way our



schedules can mesh so we can share some of the work?"

Do try to approach any problem as something that can be worked on together, perhaps even solved. Focus on exchanging ideas, not accusations. Put yourself in your spouse's place; trying to see things from your partner's vantage point is very helpful.

Don't adopt the attitude of "I know what's best for the child." This turns off and discourages your best ally—your spouse.

Do listen carefully to your spouse when he or she tries to communicate with you. Good listening involves focusing your entire attention on what your partner is saying without interrupting, second-guessing or looking off into the distance—tell-tale signs that you are disregarding what your partner is sharing with you.

Do develop a consistent approach to handling your child.



Nothing causes as many marital rifts as differences in how to deal with the child or what each considers best for the youngster. Be open to suggestions from your child's teacher or other professionals. They are experienced in assessing your child's capabilities and providing guidance on what or what not to do.

Do respond to things left unsaid. Stifled feelings, denial, the inability to express pain or sorrow erode your partner's personality and the spirit of the marriage.

Do become sensitive to your partner's body language. Slumped shoulders, worn looks, a dejected gaze are outward signs of inner pain. Encourage your spouse to talk it out, even express the unthinkable. Willingness to listen to each other in a secure atmosphere strengthens and deepens the bonds even when there are no easy answers.

The reader asks

Here is a timely question about gift selection. The editors have asked Terry Callahan, a special education teacher of adolescents in New York, to respond.

Q. I am having a hard time finding the right kind of presents and holiday gifts for my 12-1/2 year old son. He seems to go for babyish toys and I would like to get him things that are more appropriate but that he would enjoy, too. Any suggestions I could also use for relatives who want to send gifts?

A. Here are some gift selections suitable for boys and girls, ages 10-15:

- Board games such as Triominos®, checkers, Rack-o® (to develop/increase interpersonal behavior)
- Jigsaw puzzles (interlocking since some types that do not interlock can cause frustration)

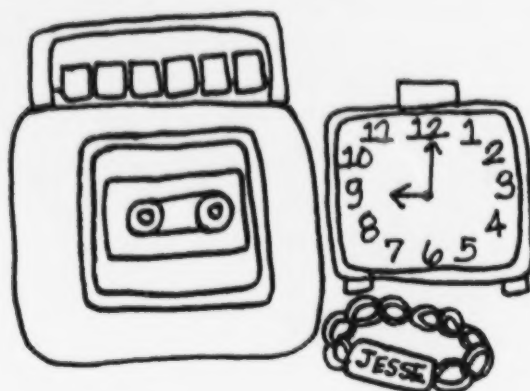
- Personalized pencils, pens, etc. (to develop the child's sense of identity)

- Coin banks (clear lucite banks that separate coins intrigue children and motivate them to save money and to practice counting)

- Wall calendars to hang in your child's room with colorful pictures depicting something your child especially likes such as dogs, cats or cars (helpful in developing time concepts)

- Posters of favorite stars or some nature scene of specific interest

- Easy-to-use tape recorders that don't require adult assistance



For older boys and girls, ages 16 and up:

- Travel grooming kits to hold toiletries
- Personal alarm clocks
- Wallets with Velcro® closures
- ID bracelets engraved with personal information
- Walkman®-style radios
- Hobby and craft supplies such as simple-to-operate cameras (disc or Polaroid®) and film, coin collecting books, latch-hook kits,

simple model kits (depending on the level of functioning, this may be an ideal way to introduce the child to leisure-time activities)

- Clothing items fashionable for teenagers

For older boys:

- backpacks
- electric razors
- after shave or cologne

For older girls:

- jewelry items
- clear nail polish
- colognes suitable for teenagers
- shoulder strap handbags

Another appropriate holiday idea is to start a holiday club/vacation club in your youngster's name at a local bank. This will give your child some idea about banking and will help him or her to get into the good habit of saving up and selecting gifts for others.

PSYCHOLOGIST'S CORNER

Being the single parent of a special child

by George Popper,
Ph. D.

Single parenthood is difficult under the best of circumstances, but is even more so for the single parent of a disabled child. Added to the usual problems of being single, managing a household and earning a living are special situations, stresses and feelings and the often lonely struggle with the needs of the special child.

Typically, single parenthood occurs because of divorce. Having a child with special problems can create stresses that contribute to the dissolution of a marriage. Whatever the circumstances, a marriage that ends in divorce can lead to feelings of anger, frustration and guilt with children caught between feuding parents fighting each other for control.

When the child has special problems, the dispute can be over who gets the child, not who wants the child. Children of divorced parents often feel they are in some way responsible for their parents' breakup. For the handicapped child, this reality can be painfully true. It is easy for such a child to become the target of the single parent's frustration and anger, particularly when it is believed—even mistakenly—that the child was the catalyst for the divorce. Single parents must be on the lookout for such feelings and learn how to cope with them even if that means seeking professional help.

The additional problem of "heroism" occurs when the single parent starts to believe the myth

that he or she is capable of doing everything alone and doing it perfectly. Although many people rise to the challenge of single parenthood, it's unlikely and unfair to expect the single parent to manage completely on their own. When these "super parents" don't fulfill the expectations they have for themselves, problems are sure to follow: denial that anything is amiss; anger focused on those they believe are thwarting their efforts; anger with themselves at having failed; or anger projected onto the child they've come to see as the source of their frustrations. It's important to recognize these possibilities as natural human reactions to stress and seek help and guidance.

The role model question needs to be considered as well: can a single parent be both mother and father to the special child? The single mother might want to consider getting help from men in the family—uncles, brothers or older cousins. If the child has a positive relationship with the estranged spouse, it should be strongly encouraged. The most important role model any parent can provide is that of a loving, caring individual who teaches a child to cope with the problems of day-to-day

living and gives the child a sense of values that will help him or her function in our society.

At some point many single parents find they need a social life or may wish to start dating again, a difficult situation even with a normal child. Consequently, some single parents convince themselves that others will be alienated because of their handicapped child and dismiss the idea of re-marrying or ever having someone in their life again. Some single parents try to convince themselves that they really don't want a relationship other than the one they have with their children and occasionally that line of reasoning works. Being single and having a special child can be a disadvantage, but it doesn't mean that you should isolate yourself from social opportunities. Recognizing that you too have needs and learning how to fulfill those needs without guilt will make you a happier person and a more effective parent.

For all of its difficulties, single parenthood can work, but know your limitations. It's important to share the load with others who can help you and your children—support groups, mental health professionals and educators.

